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PURPOSE: The purpose of this document is to offer guidelines for providing genetic services to individuals and their families served in DDSN Regional Centers.

BACKGROUND: Genetic services are part of the total service plan for people with mental retardation/related disabilities (MR/RD). Through genetic services, individuals with MR/RD and their families can receive valuable information about the nature and complications related to the disability, its origin, its implications and options for future service and treatment needs, and the risk to other family members for having children with the same condition. Genetic services are a major component of the department's prevention efforts. The need for genetic evaluations will be determined by the genetic team.

GENETIC TEAMS: DDSN contracts with the Greenwood Genetic Center (GGC) to provide genetic services to individuals and their families who receive DDSN services. Genetic teams are assigned to satellite offices around the state. Each team consists of a geneticist (physician) and a genetic case worker (usually a nurse but may be another discipline). The teams provide genetic evaluations, counseling, and follow-up to individuals and families served by DDSN.

GENETIC EVALUATIONS: As a part of services provided, each individual served in a regional center will be assessed to determine the need for genetic evaluation. The assessment and evaluation may consist of any or all of the following:

- 1) A review of medical and social records
- 2) An interview with the family

- 3) A physical examination by the geneticist
- 4) Appropriate photographic or video graphic documentation
- 5) Laboratory tests

It is the responsibility of the designated regional center staff to notify the genetic case worker located at the closest GGC office of new regional center admission and to arrange access to appropriate admission information, including medical and social records. The genetic case worker will work with regional center staff to arrange evaluations of individuals already residing in a regional center.

The genetic case worker will review all records of newly admitted individuals and will schedule appropriate evaluations. Results from the evaluation will be maintained in the individual's 20-tab record and filed under "Medical."

GENETIC COUNSELING AND FOLLOW-UP: Counseling and follow-up with the individual or his family regarding the results of the evaluation will be made by the genetic team. Results should be discussed with the individual, as appropriate. The genetic team will send copies of correspondence with individuals/families to the regional center for placement in the individual's 20-tab record.

MEDICAL REPORT: The geneticists providing this service for DDSN are physician geneticists (if Regional Center physician does not write orders) and should write orders for tests on the Physician's Orders in the individual's unit record. (The geneticists should clearly state that the tests were "done" to prevent staff from repeating the tests.) After the evaluation, it is the responsibility of the facility physician to provide a summary report (verbal or in writing) concerning positive genetic findings to the interdisciplinary team for discussion during the team meeting. Each regional center should assure its physical examination form lists "genetic evaluation" to remind the center physician of the need to record genetic results.

PAYMENT FOR GENETIC SERVICES: Facilities will bill private health insurance companies and/or Medicaid for covered services. Neither the individual nor his family will be billed for portions of genetic services that are not reimbursable through insurance or Medicaid.

KNOWLEDGE/CONSENT OF GENETIC SERVICES: As one of several components of a complete physical examination for an individual with mental retardation, a separate consent for genetic services is not indicated for individuals residing in a DSN regional center. However, to prepare families for this and other medical services, the "Regular Residential Admission Understanding" has been revised to include consent for genetic services as well as other medical referrals upon admission. The "Request for Services Agreement" has also been revised to include permission to videotape the individual, a method commonly used by geneticists to establish a diagnosis. When revising regional center brochures or other literature for families, genetic services should be mentioned as a service provided by the center.

If an individual or family refuses to consent to genetic services or if an individual does not want the results shared with family members, the wishes of the individual/family will be respected. Documentation of the genetic services refusal should be placed in the individual's record and the genetic team should be notified of such refusal.

STAFF KNOWLEDGE: Regional facility administrators are responsible for sharing the content of this procedural document with staff upon implementation. The purpose and benefit of genetic services will be incorporated into the revised staff orientation curriculum.

QUALITY ASSURANCE: It is the responsibility of the Regional Facility Administrator to assure that the content of this procedural document is incorporated into existing medical/nursing manuals; forms and materials are revised as indicated; and staff are knowledgeable about the content of this document.

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